



**ISG Parent Action Council**  
**April 13, 2006**  
**Meeting Minutes**

**Attendees:** Barbara Bower, Cecilia Bustamante, Art Gode, Linda Hamman, Ginny Love, Renee Nichols, Kim Stamper, Mark Trombino, Marta Urbina

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
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<p><b>Pre-meeting notes</b></p>	<p>The 4-13-06 ISG Parent Action Council (PAC) Meeting was a brainstorming and working meeting. The PAC has completed their May 2006 Status Report to the ISG Task Force. You can view this status report via the Parent Action Council link at <a href="http://www.azis.gov">www.azis.gov</a>. Also, look for the new link titled "Links to Grant Partners" which is the Internet Resource Listing for all partnering agencies and organizations in the IS Grant.</p> <p>The purpose and goal of the PAC is provide a single informational resource about all activities involving parents throughout the state, and to facilitate cross training, and mentoring of all parents. The Council will review local activities and make recommendations to the Task Force.</p> <p>As Year Two of the IS Grant begins, the Parent Action Council does and will play an integral part in establishing a family-friendly, community-participating, and parental-involving atmosphere for all ISG documentation and activities. To this, the PAC is a key entity for reviewing potential TF recommendations from other ISG subcommittees, giving advice and input on documentation and activities brought forth from all ISG committees, researching best practices in relation to hospital grievance and appeal policies, and collaborating with Community Development Leaders to cross barriers at state agencies.</p>	<p>*Visit <a href="http://www.azis.gov">www.azis.gov</a> for ISG-Parent Action Council May 2006 TF Status Report, and updates on other subcommittees</p> <p>*Click on the new "Links to Grant Partners" to link to all ISG partnering agencies' and organizations' websites.</p> <p>*Handouts from 4-13-06 PAC Meeting:</p> <ul style="list-style-type: none"> <li>• Draft Training Tracking Form (for review &amp; feedback)</li> <li>• Action Planning Matrix</li> <li>• Family Profile</li> <li>• Current PAC member listing</li> </ul> <p><b>*May 2006 ISG-PAC Task Force Recommendations:</b></p> <p style="padding-left: 20px;">* Any products/resources produced by other committees should flow through the ISG PAC for their review related to family perspective</p> <p style="padding-left: 20px;">* Identify medical professional(s) willing to partner with the PAC in acquiring hospital grievance process as well as developing "family friendly" versions.</p>
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		The ISG PAC has taken the initiative to expand upon their Community Action Planning Matrix (also on <a href="http://www.azis.gov">www.azis.gov</a> ) to include the "Hospital Grievance Project". The PAC should be commended on recognizing this issue as an area for improvement, and taking the first steps to begin a research and quality improvement activity.	*Identified "Hospital Grievance Project" as ISG Year Two objective (while maintaining current goals of ISG).
<b>Welcome and Introductions</b>	Marta Urbina, ADHS- OCSHCN	Welcomed all the PAC members to the April 13, 2006 meeting. All participants took a moment to introduce themselves.	

<b>Community Development Approach Presentation and Discussion</b>	Group discussion	<p>A PPT presentation on the OCSHCN Parent-Led Community Action Teams was given to the ISG Parent Action Council. This presentation helped the Council to understand the values, philosophy and activities of the OCSHCN Community Development program, which is one of the current functioning units of the OCSHCN office.</p> <p>It was noted within discussion that Community Action Teams (CATS) are succeeding with integration via independent living centers that have central locations and abundant resources to share. Kingman is a prime example. It was pointed out that the historical norm was that the center could be the place for all centralized information and access, however that is not the case in rural communities or in circumstances whereby parents must go to a primary care physician in Sierra Vista (for example), but then the neurosurgeon is in Phoenix, and the surgeon is in Tucson. Even with HIPAA and the law, there should be better coordination of the information that <i>can</i> be coordinated.</p> <p>If a CAT makes it work, what do communities do if a CAT does not exist? As parents, how do we ensure how things need to be connected? Parents who experience redundancy of services or lack of services and must advocate on behalf of their child, can help define what should be in place.</p> <p>Communities may need a central point. Agencies drive the definition of community-based. Decentralization is driven by where the money is coming from and the people competing for these limited dollars. There is a certain lack of incentive for communities that do not have the resources, to try and obtain the resources. It is difficult for families when the dollars are what drives/directs where children need to go for the care. Parents learn to manipulate systems because they want the best for their children. The obligation for this group is to promote competition for the benefit of children, not for competition of dollars.</p> <p>As parents, we know how to manipulate in order for our children to get food, appropriate, efficient care. We must be the voice for families that don't know the system. Teach them how to manipulate. We want to help fix these systems.</p>	<p>*Visit <a href="http://www.azcommunityactionteams.org">www.azcommunityactionteams.org</a> website for information on the OCSHCN Parent-Led Community Action Teams.</p> <p>*Central point for resources and information</p> <p>*Rural communities need a central location for resources</p> <p>*What needs to be shared? Does HIPAA impact the sharing we are talking about (even with a parental release)?</p> <p>*What happens when there is no Community Action Team in place?</p> <p>*Funding that dictates where children need to go for care leads to decentralization and lack of incentive to obtain resources.</p> <p>*Parents become the advocates and can help define what should be in place.</p> <p>*Obligation of PAC is to promote competition for the benefit of children, not for competition of dollars</p> <p>*Teach parents how to manipulate the systems. Be the voice that teaches.</p>
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<b>Orientation of the Integrated Services Grant website</b> <a href="http://www.azis.gov">www.azis.gov</a>	Ms. Urbina	The IS Grant website ( <a href="http://www.azis.gov">www.azis.gov</a> ) was reviewed. This gave the PAC the opportunity of hands-on viewing of current ISG documentation for this working session.	
	Group discussion	While reviewing the ISG website, the points of concerns raised by the PAC were as follows: * Re-iterate to ISG subcommittees that PAC is delegated to review all documentation recommended to the Task Force. * PAC to reach out to other parents on committees (alignment with the Young Adult Transition Committee (formerly the ISG-Youth Action Council) * How do/will other groups interface with PAC? * Insurance Committee – what ideas can we give them * Engage other families * Engage schools and districts * Partner with agencies/organizations (PPSA, Justice, DES-DDD, Blake, Indian Health) See new <a href="http://www.azis.gov">www.azis.gov</a> link entitled “Links to Grant Partners”)	*Any documentation developed by all ISG subcommittees must flow-through PAC for review. *Involve parents from other committees – ISG Young Adult Transition Committee linkage *July 20, 2006 Young Adult Transition Committee meeting will address the agenda item of “parent invite to PAC”. *ISG Insurance Committee will be earmarked for ISG-PAC involvement *Engage families, schools, districts *View “ISG Partnering Internet Links” at <a href="http://www.azis.gov">www.azis.gov</a> for collaboration ideas *Does PAC want to re-initiate it’s “volunteer flyer” to recruit parents? Can be issued within ISG Committee Meetings.

<b>Finalize Draft Documents – Family Profile</b>	Group	The PAC reviewed the draft copy of the “Family Profile”. The final version was approved with no additions or deletions.	<p>*PAC approved the final version of the Family Profile. This will be posted on <a href="http://www.azis.gov">www.azis.gov</a>.</p> <p>*PAC “Family Profile” will be shared with ISG Cultural Competency Committee at its 7-26-06 Meeting</p> <p>*PAC will provide input and review on the ISG Cultural Competency’s “Community Survey”</p>
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<b>Tasks Matrix of the Parent Action Council</b>	Group discussion	<p style="text-align: center;">Continue</p> <p>As the PAC outlined a new task/goal of the “Hospital Grievance Project”, the members began a brainstorming session. Notes are as follows:</p> <p>Every hospital has a Quality Improvement document or a Human Resource document that regulates the hospital. There are written guidelines. What are they and can we get them. This is a starting point.</p> <p>It was noted that hospitals have a way of manipulating a family into NOT filing a grievance and that the medical profession can sometimes pit families against the political environment. Hospitals and/or providers doing no more than is necessary under the law. It is a continuity of care issue between hospitals and providers.</p> <p><i>Recommendation: The PAC recommendation is that all providers include parents in all complaint interactions.</i></p> <p>We want to take this completely through the complaint process.</p> <p><i>Recommendation: The right to a Grievance filing and/or process should be available to everyone/anyone by the hospital having a copy provided at check-in.</i></p>	<p>*Choose hospitals  *Obtain hospital Grievance Policy or document that serves as Grievance Policy  *Are they current?  *Does federal ADA Law have to be revisited?  *How to use regulatory process if applicable</p> <p>*How are providers involved? At the hospital level? Would it be a provider complaint or a hospital complaint?</p> <p>Specifics:  *St Joseph’s is not pediatric-minded regarding supplies (i.e diapers)  *Sierra Vista hospital not really equipped to handle special needs – how are rural communities in need?</p>
			<p><u>Recommendations:</u>  *all providers include parents in all complaint interactions.  * The right to a Grievance filing and/or process should be available to everyone/anyone by the hospital having a copy provided at check-in.</p>

<b>Questions / Discussions / Next Steps</b>		<p>NEXT STEPS:</p> <ul style="list-style-type: none"> <li>*Get each of the hospital processes to the PAC</li> <li>* If the hospital has no protocol established, the issue could get high profile.</li> <li>*PAC could then have a “family-friendly” version of the original document (tracking deletions and additions)</li> <li>*Developing family friendly version will help align the next piece of the process (beyond the hospital entity if necessary)</li> <li>*Involve behavioral health families</li> <li>*Call Mental Health Association for involvement</li> <li>*Bob from FIC</li> <li>*Families that have Sickie Cell</li> </ul>	<ul style="list-style-type: none"> <li>*Call Mental Health Association for involvement</li> <li>*Bob from FIC</li> <li>*Sickle Cell families <ul style="list-style-type: none"> <li>-Can invite Sickie Cell families to October 2006 PAC meeting (Quest to Cure-Kristine Buchanan)</li> </ul> </li> <li>*Potential for the PAC’s Hospital Grievance Project to become high profile, especially in a case whereby no grievance policy or protocol is in place.</li> </ul>
<b>Next Meeting</b>		<b>July 13, 2006 11am-2pm ADH Bldg, Room 345A</b>	